ALBERTA'S HOME CARE PROGRAM

Self Managed Care Pilot Project Evaluation

Executive Summary

Alberta
HEALTH

Over the past several years, many individuals, consumer and advocacy groups have recommended that Alberta Health develop a Self Managed Care option for Alberta's Home Care Program. This method of service delivery would recognize the importance of enabling people to be active participants in meeting their care needs. People would be assessed as needing support services and then provided with the funds to hire their own service providers. Principles of consumer responsibility, choice, control, right to risk and empowerment would be key features.

In April of 1991, a decision was made to test the feasibility of providing this option within the structure of Home Care programs and, if so, how it could best be offered.

A Self Managed Care Project Advisory Committee was established in June of 1991 to make recommendations on a framework for the implementation of the Self Managed Care Pilot Project. This committee was composed of representatives from a variety of stakeholder groups. The design for the Self Managed Care option was completed by the fall of 1991. The Self Managed Care Pilot Project was then implemented in four of Alberta's health units (Edmonton Board of Health, Calgary Health Services, Red Deer Regional and South Peace). A comprehensive evaluation, with a strong client focus, was a central component. Over 80 people participated in the pilot, although only 39 were formally included in the evaluation.

Throughout the pilot, refinements and modifications to the original design were incorporated. The Advisory Committee met regularly to make recommendations about emerging issues.

The evaluation was conducted by an independent evaluator and overseen by the Advisory Committee. It was completed in March of 1993. The findings were predominately very positive and supported the province-wide implementation of Self Managed Care.

In April of 1993, Alberta Health recommended that all health units across Alberta incorporate the Self Managed Care option into their Home Care programs.

This is a summary of the results of the pilot project.

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What is Self Managed Care?

In a few words, Self Managed Care is an option within Home Care programs where individuals assume responsibility for meeting their assessed personal care and support service needs. Professional health services required by Home Care clients are not provided as part of Self Managed Care.

People who need personal care or support services are assessed by a Home Care coordinator and the service plan is developed, based on the needs of individuals. If a client is interested in Self Managed Care, the client and the coordinator discuss the responsibilities and conditions and a "Letter of Agreement" is signed. The individual receives funds from the health unit, on a monthly basis, to purchase the required services. The individual becomes the employer and is responsible for hiring, training and supervising staff. The employer/client is also required to maintain financial records and comply with labour and employment standards.

A person on Self Managed Care is, first and foremost, a Home Care client so the general Home Care Regulations apply. As with all Home Care clients, an annual reassessment of the care plan is required. Other case coordination activities will vary, depending on the needs of the client.

Understanding the Project

Background

Too often, programs are established with the best of intentions for individuals — but administered with little regard for the needs of that specific individual, while also limiting the flexibility and creativity of the providers to respond on an individual basis . . . . In the past, when we developed an illness, had a disability, or required health care services, we were considered "sick," and assumed to be less capable of making well-informed decisions about complex, or even simple issues. As a result, medical information was often kept from us and decisions were made on our behalf . . . . What has happened to change our relationship with health care providers? Knowledge. As more information becomes available, awareness and understanding among us increases. We want to be in the position of making informed choices about the options available to us in regard to our health care needs. We want to be involved as partners with caregivers in determining who will

provide treatment, what that treatment should be, where it will occur, and how much intervention we are willing to accept. We, as individuals, want to be in control.

The Rainbow Report: Our Vision for Health, p.65

These comments epitomized a growing realization in Alberta about the need for shared decision making in client care. Alberta's Home Care Program was a logical choice to explore this concept. Home Care philosophy stresses that health-related decisions lie with individuals, personal support networks and community resources first. Home Care provides supplementary services to ensure that these needs are met.

In July 1991, the eligibility criteria for Home Care were expanded to provide support services to people under the age of 65, regardless of their need for professional health services. The Alberta government was committed to developing an equitable and accessible service which was not influenced by age, income, residence or type of disability. Home Care was available province-wide, was linked to the health units and provided generic services, therefore it was seen as a primary player in the provision and shaping of services for persons with disabilities. In the short term, the focus was to ensure that program services were more easily accessible for persons with physical disabilities. The primary responsibility for supporting persons with mental disabilities remained with Alberta Family and Social Services. Home Care would continue to provide professional health services (if required) to persons with mental disabilities.

The Home Care Issues Review Steering Committee was established in 1989 under the chair of the Assistant Deputy Minister, Policy and Planning Division, Alberta Health. This committee reviewed the concept of individualized funding. In January 1991, the Minister of Health approved the Self Managed Care Pilot Project for immediate implementation. The Self Managed Care Project Advisory Committee was established in June 1991 to recommend a framework for the implementation and evaluation of the pilot project.

Definition

The Home Care program is administered at the provincial level by the Home Care/ Community Long Term Care Branch of Alberta Health.

The boards of directors for each of Alberta's 27 health units are responsible for administering Home Care program funds provided by Alberta Health. Boards manage their own programs, within provincial guidelines.

Home Care was originally offered as a direct service, providing staff (or vendor

agencies) to offer personal care, home management and professional services. The actual time of visits to clients could vary from day to day, depending on the staff or agency's case load.

As an option to direct service, the Self Managed Care Pilot Project set objectives that were to:

- provide Home Care clients with the opportunity to receive funds to manage their own support services;
- increase the opportunity for Home Care clients who selected this option to increase control over their lives and enhance their personal dignity and wellbeing; and
- demonstrate the effectiveness (of both quality and cost) of Self Managed Care.

Self Managed Care Pilot Project Design (1991), p. 3

Assessment

Acceptance to the pilot depended on clients fulfilling the same criteria as individuals wanting direct service from Home Care. Eligibility required that clients:

- were eligible for Home Care;
- needed service for a reasonable length of time (e.g. one year);
- had their immediate professional care needs met (Home Care clients who were in an unstable, acute episode which required nursing or other professional intervention were not offered this option); and
- chose to be on Self Managed Care.

Potential clients who wished to manage their own care completed a questionnaire, "Is Self Managed Care for Me?" to review whether they had the necessary skills and abilities.

These skills included the ability to:

- recruit;
- interview;
- hire and fire;
- manage conflict;
- manage finances;
- negotiate; and
- supervise.

In addition, clients had to consider if they were willing to assume the

responsibilities and risks associated with the option and if training would be necessary for their success.

The total potential monthly funding available to a Self Managed Care client was the same as for clients on direct service. This was a maximum of $3,000 in total for both professional and support services. The allocation of funds depended on the clients' assessed needs, in relation to the resources of each health unit's Home Care program.

Agreement and Implementation

A "Letter of Agreement" was used by the health units. It set out both the client's and health unit's responsibilities. In the case of clients who were under the age of 18, or had legal guardians or trustees, the guardian or trustee could sign the agreement. This person would be accountable for the money received from the health unit and the purchase of services. If a client's needs changed, the case coordinator and client would jointly review the situation, determine what changes were required and amend the agreement appropriately.

People who required skill development to use this option received their services directly from Home Care while they pursued the necessary training and experience. Case coordinators were not responsible for teaching clients necessary skills but they provided support through referrals to a training resource.

Clients who did not want to be employers could hire an existing care provider service (vendor agency).

Financial accountability was critical. Self Managed Care clients were required to maintain the records outlined in their "Letter of Agreement" and keep a bank account solely for Home Care funds. These records were to be available for periodic review and verification by the health unit. The health unit would review the financial records of a sample of Self Managed Care clients each year to ensure that funds were spent appropriately.

The quality of service was also to be assured through evaluations of both the case coordinator and the client. They agreed on:

- how frequently the services would be assessed;
- whether the appropriate quality was being provided;
- how well the client was coping;
- if levels of service remained appropriate; and
- if the client's needs had changed.

It was expected that clients would advise their case coordinator when their service

needs or conditions had changed. If a new care provider was required, the client would make the necessary arrangements.

If a client wished to withdraw from Self Managed Care, reasonable notice was required unless it was an emergency. A client could return to the Self Managed Care option if, following another assessment, the case coordinator felt it was appropriate. The case coordinator could move a client to direct service if there was a misuse of funds or another breach of the "Letter of Agreement."

The pilot program was implemented between January 1992 and March 1993 in four of Alberta's health units: Calgary, Edmonton, Red Deer and South Peace. These sites were selected to provide a mix of rural and urban experiences. The evaluation occurred between February 1992 and March 1993.

Evaluation

Two committees guided the implementation of the Self Managed Care pilot project and its evaluation.

The Evaluation Advisory Committee had representation from Alberta Health, the health units, Alberta Family and Social Services, the Premier's Council on the Status of Persons with Disabilities and the University of Alberta. Its purpose was to guide the evaluation process and provide feedback to the independent evaluator.

The Implementation Advisory Committee, with representatives from each of the four pilot sites, Alberta Health and the consumer community, shared implementation information and discussed issues as they emerged.

It was planned that the pilot would be expanded province-wide on April 1, 1993.

Literature Review

A review of the literature in the Home Care field revealed similar issues in the area of long term care.

The American and European experiences were examined and three models of long term care were identified, the:

- Medical Model;
- Informal Support Model; and
- Independent Living Model.

The Independent Living Model was explored in depth. A variety of related topics (including the use of advocacy, the independent living movement, issues regarding personal care attendants and the concept of brokerage systems) were explored and

two Canadian examples of independent living programs (the Alberta Polio Program and the Manitoba Project) were outlined.

It was found that over the past few years, there has been a move away from the Medical Model of long term care. But the Independent Living Model has a number of associated issues which need to be resolved including:

- the control versus risk dilemma;
- quality assurance measurement concerns;
- training for clients to be employers; and
- use of family members as care providers. While this is generally accepted as the most common form of care, it is largely unmonitored, ill-defined and unpaid.

The conclusion reached was that the Self Managed Care Pilot Project was positioned to define new territory in the management of independent living for long term Home Care clients.

Evaluating the Project

Purpose

The evaluation was to:

- provide Alberta Health, as well as other stakeholders such as health units, Alberta Family and Social Services and non-profit agencies, with information to assist in the refinement of this option to ensure its smooth functioning by April of 1993 when some clients from Alberta Family and Social Services would come under the jurisdiction of Home Care; and
- obtain baseline information related to project outcomes, including clients' sense of control, personal dignity and well-being.

Two models were used. One was related to process and focused on the implementation and outcomes of the pilot project. The other depicted the environment for clients in the form of a map which delineated their relationships with a variety of groups. Based on the purpose and these two models, evaluation objectives and research questions were developed and compiled in a data collection matrix. This was to be the backbone of the research process.

A multi-method, qualitative approach was taken to evaluate this complex project. Many stakeholders were involved and information was available from a wide variety of sources in a number of locations in Alberta.

Methods that were used included:

- a document review;
- a review of the literature;
- on-site observation;
- a file review;
- demographic analysis; and
- an extensive series of interviews.

In particular, interviews were conducted with:

- key project initiators;
- clients in the project and their families;
- care providers;
- case coordinators;
- health unit administrators; and
- relevant Alberta government staff.

The results were compiled into four case studies, documenting project implementation at the four pilot sites. A cross-case analysis was also conducted. Project outcomes were documented and tracked. Project issues were identified and recommendations for further action proposed.

Limitations

There were some evaluation limitations identified including the:

- nature of the pilot (this included the short time frame — the length of the study was not long enough to fully measure the impact);
- positive bias (clients opted into the program);
- "Hawthorne effect" (clients knew that they were participating in a pilot project); and
- method of selecting clients (case coordinators tended to invite clients they thought would be appropriate).

Limitations relating to methodology included that:

- documents were not complete
- information in clients' files (for example, the "Is Self Managed Care For Me?" form) was not always available;
- the "snowball" technique, used to nominate interview participants, was not

necessarily comprehensive. It is possible that valuable potential participants were not included;

- interviews were potentially limited by memory lapses of participants;
- self-reported data may have been biased; and
- the evaluator was unable to judge the completeness or accuracy of the information provided.

However, these limitations were minimized by the rich and composite nature of the study design. Perceptions were collected from many participants and stakeholders over time as:

- early clients were interviewed twice, with a five to six month interval;
- health units were visited twice, with eight months in between; and
- some administrators were interviewed twice — at the beginning and again at the end of the study.

This revisiting process was particularly appropriate for a qualitative study. It enabled the researchers to collect complex and dense information that was useful in determining how the pilot was implemented and how it had affected clients.

Findings: Project Implementation

A detailed description of project implementation at the four pilot sites is provided in the *Self Managed Care Pilot Project Technical Report*. Highlights were compared in a cross-case analysis of topics such as client age, gender, responsibility status, disability conditions, reasons for selecting or rejecting Self Managed Care, service profile, employment problems, and the system and procedures.

Clients

The analysis revealed that there were many similarities across sites including that:

- clients tended to be female;
- the mean age was 41. Exceptions were noted in Edmonton where those clients who came on the pilot later were older (mean age 75), and in South Peace where a child client lowered the mean age to 25;
- about 66 per cent of the clients were responsible for managing their own care (except in Edmonton where 56 per cent managed their own care);

- the most frequently recorded disabling conditions for clients were quadriplegia/paraplegia, Multiple Sclerosis/Muscular Dystrophy and neurological disorders;
- clients generally selected this option for the following reasons:
  - financial;
  - they wanted more control, more consistency and more flexibility over their care; or
  - they were dissatisfied with their current care arrangements.
- potential clients rejected the option because:
  - they were anxious about the volume of paperwork involved;
  - they were satisfied with current care arrangements; or
  - the option required too much effort.

Self Managed Care clients were assessed more frequently, and to a greater extent, for personal care rather than homemaking support. However, clients reported that they spent less on personal care support and more on homemaking support than had been assessed. Assessments and expenditures varied but, on average, clients spent $183 less each month than they were allocated. The total mean expenditure was $1,170 per person per month.

Early in the pilot, there were few employment problems were reported. During their second interviews, 21 per cent of clients reported that they had fired their care providers. More employment problems were reported in Calgary and Edmonton than in the smaller centres. Nearly half of the urban clients reported employment problems such as attendance or tardiness. Concerns about quality of care or interpersonal conflict were seldom mentioned.

Health Units

Administrative procedures among pilot sites were comparable and completed in nearly all cases. The only start-up activity which was not frequently reported was the discussion of training needs at 66 per cent. This activity ranged from 43 per cent in Red Deer to 100 per cent in South Peace.

Despite initial hesitation on the part of accounting staff regarding potential time requirements, all four sites reported that the actual demands of the option had been minimal. Accounting systems emerged throughout the year. Red Deer Regional Health Unit provided leadership in this area. Generally the financial review process was not well addressed (with the exception of Red Deer). There was a lack of clear policies in each health unit to identify how to review clients' books and who was responsible for that review, (i.e., accounting staff or Home Care staff). In addition, it was not clear who was responsible for program funds once

they had been allocated to clients (i.e., the health unit or the client). As year end approached, the health units remained unclear about accountability for project funds and about the process required to review clients' books.

The cross-case analysis led to the conclusion that the implementation process at the local level reflected the proposed model and followed it very closely. The only area where discrepancies were noted was for training referrals. This was not surprising as training supports varied by site from excellent (in Edmonton) to non-existent (in Red Deer and South Peace). Clients varied in their training needs. Some required no help; others were intimidated by the demands of being an employer. At least two potential clients rejected the option for this reason. It is clear that training support would enhance adoption of Self Managed Care.

Few gaps were identified between proposed and actual project implementation at the local level. The nature of clients who came onto the pilot later, and hence were interviewed only once, was somewhat different (they were older, more dependent). But, it was impossible to tell if this was a trend or a variance from the norm. Generally, clients spent about 86 per cent of their allocated funds. This small surplus provided a cushion for unexpected changes in care needs.

Provincial View

The implementation of the option at the provincial level was also briefly reviewed. It was important to determine if the project had adhered to relevant statements from the Alberta government document, *Caring and Responsibility, A Statement of Social Policy,* which was from the Alberta Health's Mission Statement, and from the principles and operating guidelines established for the Self Managed Care Pilot Project.

Nine of the 13 guiding principles outlined in these documents were very successfully achieved, including:

- innovative leadership;
- stewardship of resources;
- equal participation in quality of life;
- support and resources for initiative, self-reliance and self-sufficiency;
- dignity for the service recipient;
- maintain and support social network;
- client focus;
- flexible and responsive to changing client need; and
- continuous program review and operation.

The remaining four principles were followed to a certain extent but limitations or gaps were identified between planning and implementation. These included:

- personal choice, individual responsibility and right to risk
  (because clients were unable to select family members to give care, the professional barriers restricting choices of clients regarding certain professional services and the pre-screening by some health unit staff);
- training and support not a duplication
  (the lack of available training may have been a barrier to entering the program);
- existing Home Care Regulations apply
  (the inability of some clients with complex 24 hour care needs to return to direct service); and
- straightforward operation
  (there was greater program success where community support for clients as employers was provided).

Findings: Project Outcomes

Outcomes identified in the pilot were related to:

- the clients' ability to manage their funds;
- the impact on clients, their families and care providers;
- the satisfaction of all stakeholders with the process;
- achieving the project's goals; and
- unanticipated outcomes.

At the time of their follow-up interviews, 46 per cent of the 28 clients interviewed reported that they were able to manage funds on their own. The remainder, 54 per cent, felt that they could manage with some assistance from family, friends, an agency or some other source. Clients more often utilized family than any other assistance in managing their funds. Generally, clients (69 per cent) reported being very comfortable with managing their own care funds.

Of the 15 support people, there were 14 (or 93 per cent), along with 10 of the 12 case coordinators (or 83 per cent) who expressed confidence that Self Managed Care clients could manage funds effectively. The administrators were quite positive in their views. There were few negative comments. Once the system was setup, it appeared to function smoothly and only one or two minor problems were

identified. Some administrators did feel that it was too soon to tell what the outcome would be.

Generally, the greatest positive impact of Self Managed Care was noted in the clients' increased sense of personal control. Impact on personal control received the highest ratings across all groups. Increased freedom, independence and control in their lives accounted for over 30 per cent of all comments provided by clients. The least positive appeared to be the impact on clients' health which received the lowest ratings. These ratings were still positive. Two clients indicated that they felt better physically since beginning the project.

The most common impact, reported by family and support people, was that this option reduced stress and allowed them to be more relaxed. Improvements were frequently reported with financial situations, home life stability and personal relationship with their spouse.

Care providers most commonly reported that their employment situations were more relaxed than working for an agency or hospital. They had developed a close, personal relationship with the Self Managed Care client. Increased self-awareness and of the challenges and abilities of people with disabilities were also reported.

Case coordinators most commonly cited increased client independence and control had an impact on them personally. They also reported that they were more aware of care options for clients, that their workloads had lessened and that they were dealing with fewer complaints from clients about care providers.

Clients reported a marked increase in their satisfaction with the quality of care. Family and support people also reported being considerably more satisfied with the care. Care providers indicated they were very satisfied with their employment situations. Case coordinators were generally satisfied with the process.

The primary advantages reported across all groups were and increased independence and sense of control experienced by clients.

The most commonly cited difficulties were the responsibility for bookkeeping and payroll and problems in finding appropriate staff.

Findings: Project Goals

1. To provide Home Care clients with the opportunity to receive funds to manage their own support services.

All clients on Self Managed Care reported receiving their allotted funds. Generally, family members and case coordinators perceived that clients were managing their own funds. In fact, 46 per cent of clients reported managing independently and 54 per cent indicated that they had received some assistance. Nearly 70 per cent of clients were very comfortable with funds management and all but one of the remaining clients were "somewhat comfortable." The system for providing clients with their own care dollars appeared to work very smoothly.

2. To increase the opportunity for Home Care clients who select the Self Managed Care Pilot Project to increase their control over their lives and enhance their personal dignity and wellbeing.

All groups reported that the sense of personal control improved markedly for clients. The impact on the happiness and self esteem of clients was positive and some perceived a positive impact on their health. Clients were significantly more satisfied with their care arrangements, as were their families and support people. Care providers and case coordinators were also very satisfied with care arrangements.

3. To demonstrate the effectiveness (including both quality and cost) of Self Managed Care.

Health units could potentially provide up to a total of $3,000 for professional and support services to any client on a monthly basis. This amount was the same for all Home Care clients, whether they were on direct service or Self Managed Care. The evaluation revealed that, on Self Managed Care:

- between 14 – 29 per cent of clients spent $500 or less per month;
- between 11 – 14 per cent of clients spent more than $2001 per month; and
- between 50 – 75 per cent of clients spent between $501 and $2,000 per month on their care.

Cost-benefit issues were not evaluated in depth because of the short time frame. However, it was evident that few risks emerged while there were many health and personal benefits including that:

- clients felt they had increased independence, improved care situations and better relationships with care providers;
- family members identified less family stress;
- care providers felt more relaxed in their jobs and had better relations with their clients;
- case coordinators cited increased awareness of their clients' need for independence; and
- administrators also perceived a number of emerging benefits, although some took a "wait and see" approach.

Findings: Unanticipated Outcomes

There were also some unanticipated outcomes that tended to be positive in nature. These included surprise:

- at the ability of clients' to be empowered in managing their care. This was the most commonly expressed outcome;
- about the number of clients who were approached but rejected the option (a comment from case coordinators);
- at the low acceptance rate and the fact that different clients actually chose the project than those initially identified by case coordinators (expressed by administrators);
- about the slow acceptance of the concept by staff (expressed by administrators); and
- about the smooth nature of program implementation and at the very positive outcomes to date (a comment from administrators).

Conclusion

Most clients appeared to thrive on Self Managed Care.

Only 2 of 39 cases (or 5 per cent) were removed from the option due to funds management issues. No incidents of abuse from either clients or care givers were reported. Overall, it was evident that the benefits of Self Managed Care well outweighed the risks.

The goals of the pilot project were very well-achieved and the decision to expand the pilot to a province-wide status was supported by this evaluation.

Recommendations

A variety of issues are explored in the *Technical Report*. Many of these were resolved during the course of the pilot project while some remained outstanding. Where possible, the recommendations from the evaluation attempted to address these issues. They are that:

- Self Managed Care become a province-wide option for Home Care;
- client empowerment be ensured through the development of appropriate policies and procedures at each health unit, to clarify in what ways clients, health units and Alberta Health are accountable and responsible for funds;
- a simple, financial review process be developed and implemented province-wide to support client accountability. It is important to not create a lot of rules and regulations, but to manage those clients who require it (management by exception);
- health units consider an implementation model that provides a key contact person for Self Managed Care within Home Care. This person should be in place for at least one year after the first client selects the option and become a central resource for information and trouble shooting during the option's early development at the health unit;
- Self Managed Care information manuals be developed. These would outline the program, provide training information, local resources and evaluation findings. A binder format would facilitate updating and tailoring information to the local health unit;
- tools be developed to inform clients about employment issues such as hiring and firing and assist them in monitoring the quality of their own care (e.g., quality care checklist);
- non-profit brokerage/training/payroll support agencies be actively encouraged to act as an adjunct service in localities where they do not currently exist;
- Alberta Health develop a sub-option of Self Managed Care for clients who have family members or close personal friends managing their care. However, consideration might be given to excluding guardians who operate at arm's length;
- Alberta Health continue to pursue a satisfactory ruling from Revenue Canada to define Self Managed Care funds as medical payments or some other such non-income definition; and
- the pilot project's clients be acknowledged and thanked for their participation and their important contributions.

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